

Following Through to the End: The Use of Inclusive Strategies to Analyse and Interpret Data in Participatory Action Research with Individuals with Intellectual Disabilities

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Background Scholars have called for research approaches that actively include and are driven by people with intellectual disabilities, but the process of inclusive data analysis has been scarcely documented in the literature. This paper demonstrates the process university researchers and a group of self-advocates used to analyse and interpret data collected during a participatory action research (PAR) project to increase the group's capacity for self-advocacy.

Materials and Methods University researchers presented numerical data in three visual formats for analysis. Seventeen People First members analysed and interpreted the data using a modified focus group approach.

Results All members participated in data analysis, but not all members participated in data interpretation. Members' interpretations suggest that the group felt an increased sense of empowerment and heightened awareness as a result of their increased capacity to run a meeting and involvement in the PAR cycle of action and reflection.

Conclusions Findings suggest that strategies such as visual representation of data, group analysis, and familiarity with data collection tools foster an inclusive process of analysis and interpretation.

Keywords: inclusive research, intellectual disability, methodology, participatory action research, self-advocacy

Introduction

In the past decade, leading scholars have called for research approaches that actively include and are driven by people with intellectual disabilities (Walmsley 2001; Walmsey & Johnson 2004). As a result, it is becoming increasingly common to find articles reporting results of collaborative research studies (see for example: Bonham *et al.* 2003; Emerson *et al.* 2003/2004; Schalock & Bonham 2003; Townson *et al.* 2004; Schalock *et al.* 2008), articles discussing the benefits and challenges of implementing collaborative studies and disseminating their results (Gilbert 2004; Bjornsdottir & Svendsdottir 2008; McClimens 2008; Johnson 2009), and articles providing theoretical and methodological insights that can inform the collaborative research process (Rodgers 1999; Knox *et al.* 2000;

Chapman & McNulty 2004; Walmsley 2004; Dearden-Phillips & Fountain 2005; Schoeters *et al.* 2005; Abell *et al.* 2007; Dowse 2009; Garbutt *et al.* 2009; Kellett 2010). However, the actual procedures and key strategies used by researchers and people with intellectual disabilities to access, analyse and interpret research data have been scarcely documented in the literature (Tuffrey-Wijne & Butler 2009). Therefore, this paper aims to demonstrate the process researchers and a group of self-advocates used to analyse and interpret data collected during a PAR project to increase the group's capacity for self-advocacy.

Background

The term inclusive research has been used to describe a range of research approaches in which individuals with

intellectual disabilities collaborate with researchers to address the imbalance of power typically found between researchers and persons with intellectual disabilities (Walmsley 2004). Inclusive research is informed, among other approaches, by PAR, an approach in which people from the community are actively involved in the research process by identifying problems, collecting and analysing data, and using the results to take action (Selener 1997). This process of gathering, analysing and interpreting data can be empowering to people with intellectual disabilities by potentially raising their awareness of their situation and facilitating a desire to change that situation if they find it unsatisfactory; this is known as 'conscientization' (Freire 1970).

In the PAR process described here, inclusion meant going beyond providing basic access and ensuring the authentic engagement of people with intellectual disabilities. Authentic engagement enables people with intellectual disabilities to make links between data collected and actions taken, and to ground the interpretation of data in lived experiences. The literature includes few examples that describe in detail the process by which people with intellectual disabilities were authentically engaged in data analysis. For example, Tuffrey-Wijne & Butler (2009) described a collaborative approach to analyse qualitative data. In their study, strategies such as presenting data in smaller excerpts, having researchers without disabilities record the comments and reactions of researchers with intellectual disabilities, and comparing interpretations across multiple team members supported authentic analysis and interpretation. Dowse (2009) briefly described that the use of plain English summaries enabled access to research data, and that avoiding jargon and conducting analysis in a group context facilitated involvement in data analysis and interpretation. While many studies have included people with intellectual disabilities in the process of data analysis and interpretation, few studies provide the detail necessary for replication. We present a detailed example from a PAR project to illustrate how data gathered over 22 months were presented to a group of self-advocates for inclusive analysis and reflection as the final stage of the research process.

This two year PAR project initially began at the request of a community-based organization (CBO) that sponsored a local chapter of People First, a preeminent self-advocacy organization. This chapter, established in 1990 in a large Midwestern city, recently lost the support of state funds, yet continued to meet with the support of the CBO and two advisors without disabilities. At the start of the collaboration, the university researchers met

with People First members to reconcile the goals of the self-advocacy group with the goals the CBO had for the chapter. The resulting aim identified by group members was to increase group capacity for advocacy, starting with the specific goal of running a People First meeting.

Initial outcomes of a PAR project to increase group capacity for advocacy

One outcome of this ongoing collaboration was the creation of a 'Who Did What' checklist that enabled group members to document and reflect upon the extent to which they controlled the process of conducting a People First meeting (Garcia-Iriarte *et al.* 2008). This checklist, created in the eighth month of the project, was organized into sections representing parts of running a People First meeting, including: setting the agenda, preparing for the meeting, running the meeting, organizing materials, participating in the meeting, and making decisions. Each section included several items representing specific tasks or use of strategies, accompanied by a picture. Control was rated with a scale that indicated 'who did what'.

On a meeting to meeting basis, the checklist enabled People First members to reflect on the events of their current meeting, identify specific goals for future meetings, and take steps to achieve their goals with support from advisors and university researchers. The checklist data gathered between the eighth and fifteenth month of the project was reported in a previous article (Garcia-Iriarte *et al.* 2008). The checklist data from that time period indicated that People First members gained some control over some but not all meeting tasks. As the PAR project came to a close after 22 months, the university researchers and People First members met to discuss the impact of the collaboration. In an effort to maintain a collaborative approach, the researchers presented their thoughts on why it was important to analyse the full 22 months of data. For the university researchers, it would provide the data to document the outcome of the PAR study. For People First members, it would serve as a way to reflect on what they learned over the course of their engagement in the project. When People First officers expressed interest in analysing the data, the university researchers said they could collaborate with People First to analyse the 'Who Did What' checklist data. Therefore, the final two questions posed in this PAR project were: (i) 'How can People First members engage in an inclusive process of data analysis and interpretation?' and (ii) 'What are People First members' perspectives regarding group capacity for advocacy over time?'

Materials and Methods

Participants

The chapter of People First included approximately 30 members, and throughout the project, a core group of 16 members consistently attended the meetings. Seventeen People First members with consent to participate in this project participated in this analysis. Members ranged in age from 25 to 56 years old, and three were female. Two members were African American, three Caucasian, and eleven were Latino/a. Seven members were bilingual (Spanish and English), and ten were monolingual (three Spanish and seven English).

All participants in this study met inclusion criteria as having an intellectual and developmental disability (I/DD) as defined within the U.S. Developmental Disabilities Assistance and Bill of Rights Act Amendments of 2000, section 102(8). According to the Act, the criteria for a diagnosis of intellectual and developmental disability includes manifestation and diagnosis prior to age 22 which results in functional limitations of three or more major life activities. People's functional status and adaptive behaviour were evaluated by qualified staff in community organizations using the ICAP (Inventory for Client and Agency Planning) (Bruininks *et al.* 1986) to determine service levels. The ICAP scores indicate a diverse group of participants, with an average score of 64.47 (SD 12.01), ranging from scores of 50 to 90 on a 100 point scale. These scores corresponded with a range of services and supports provided to members in their daily lives: regular personal care and/or close supervision ($n = 12/17$); limited personal care and/or regular supervision ($n = 3/17$); and infrequent or no assistance for daily living ($n = 2/17$). Intelligence quotient (IQ) scores were not released for participation in this project.

Procedures and analysis

Ethical approval was received from the university, and all members provided informed consent or assent to participation in this project. University researchers entered 'Who Did What' checklist responses collected between April 2006 and January 2008, a period of 22 months, into an excel file. People First members and university researchers collected checklist data during 17 of those months; some meetings were cancelled due to holidays and special events. Responses to the 'Who Did What' checklist varied; in some cases, departures from the typical meeting procedures made items not applicable and, in other cases, members chose not to complete

the entire checklist. The response categories for each item in the checklist were: 'Advisors', 'People First members and Advisors together', or 'People First members'. For each checklist item, the number of times each rating category was selected was summed to create frequencies. University researchers presented the numerical data in three visual formats for analysis:

1. Bar graphs for each item depicting rating category frequency, with pictures above each bar representing the different rating categories;
2. Pie charts for each item depicting rating category frequency, with pictures representing the different rating categories in the corresponding section of the pie; and
3. Line graphs for each item showing change in ratings over time, with pictures depicting the different rating categories on the y -axis and the months on the x -axis.

The university researchers shared each type of graph with the People First officers and asked them to identify their preferred format. The four officers indicated they liked the bar graphs, and they were able to explain in their own words the meaning of the graphs. The researchers then created one overhead slide for each item that included the 'Who Did What' checklist item, the picture associated with that item on the checklist, and the bar graph (Figure 1).

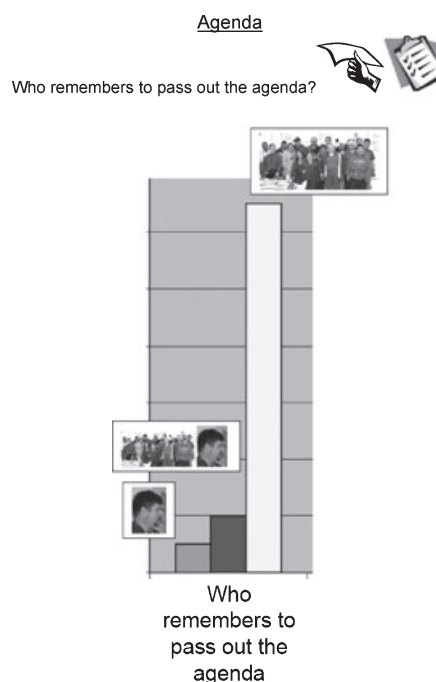


Figure 1 Example bar graph presented to People First members for analysis and reflection.

The data were presented to People First members using a modified focus group approach that created a safe environment for sharing feelings and ideas (Kamberelis & Dimitriadis 2005). People First members gathered in their regular meeting space, with an overhead projector and screen at the front of the room. The university researchers and members were divided into four small groups around tables throughout the room; small groups would provide individual members with more opportunities for sharing their thoughts. Each small group was supported by one of the university researchers or group advisor; one group was co-supported by the group's vice president. Members and university researchers negotiated to determine the best group composition. For example, Spanish speaking members were in one group supported by the Spanish speaking university researcher. Each group also included a People First member who was a past or current officer so that their experiences with responsibilities associated with the officer role and the 'Who Did What' checklist was reflected across groups. To supplement the bar graph displayed on the overhead projector, each small group also received a packet illustrating the results in the three ways described on the previous

page. To prepare the group to analyse the data, the university researchers first explained how each bar in the graph was associated with a different rating category from the 'Who Did What' checklist. The researchers also explained that for each item, the highest bar meant a category had been selected most often over the 22 months, and the lowest bar meant a category had been selected less often.

A two step process was used to analyse and interpret the data. First, the full group analysed the data associated with each item. A university researcher displayed the first overhead, read the item, and asked members to identify the tallest bar. The university researchers asked a series of iterative questions to support the analysis of the bar graph (i.e., if the 'People First Members' category bar is the tallest, what does that mean?). The researchers checked for group understanding of the bar graph based on their responses to these iterative questions; the group reached analytical consensus that the tallest bar indicated 'who did what' most frequently for that item during the study (presented in Table 1). This generated quantitative, nominal data.

The second step was to interpret this analysis. After reaching consensus on each item, the small groups

Table 1 Analysis of 'Who Did What' checklist items related to agenda, preparing for the meeting, and running the meeting*

Item	Who Did What Rating Scale**			
	A	M & A	M	DND
The Agenda				
Who thinks of items to put on the agenda?	3	9***	5	–
Who makes copies of the agenda?	–	2	13***	–
Who remembers to pass out the agenda?	1	2	13***	–
Who remembers to look at the agenda during the meeting?	1	3	12***	–
Preparing for the meeting				
Who arranges transportation for the next meeting?	5***	1	2	7
Who sets up tables in the room for the meeting?	–	5	11***	1
Who gets things out of the filing cabinet for the meeting?	1	2	9***	4
Who gets snacks and drinks for the meeting?	3	3	6***	4
Running the meeting				
Who calls the meeting to order?	–	4	13***	–
Who takes attendance at the meeting?	–	3	13***	–
Who helps us follow the agenda during the meeting?	2	10***	5	–
Who introduces new topics at the meeting?	2	9***	5	–

*Items not analysed include: Who makes the agenda in the computer? Who fills out the flyer to announce the next meeting? Who passes out flyer to announce the next meeting? Who keeps time at the meeting? Who writes down ideas on a big piece of paper?

**Rating scale categories: A = Advisors, M & A = People First Members and Advisors together, M = People First Members,

DND = Did Not Do.

***Category identified by group as most frequently occurring.

participated in a guided discussion to interpret each result using the following questions: Why do you think this happened?; What does it mean for People First?; How does this make you feel?; Are you ok with this?; What worked well and what didn't? These questions were designed to elicit in-depth information from People First members in their own words regarding their participation in the study and achievement of the goal of increasing capacity for running the meeting. This generated qualitative data.

This two step process was repeated for additional items using the same response categories. A different People First member introduced each item and ran the group analysis. Not all items were analysed; items less relevant to the members' goal of running a People First meeting were not discussed, for example 'Who passes out the flyer to announce the next meeting?' In addition, a series of checklist items used to track the use of organizational and communication strategies at each meeting (presented in Table 2) were analysed and discussed with the full group.

People First members' quantitative analyses of bar graphs were recorded on data collection sheets and transposed to table format (as shown in Tables 1 and 2). People First members' qualitative interpretations of the data were documented using handwritten field notes as well as audio recorded and transcribed. University researchers wrote separate field notes after the meeting

to reflect on the process of collaborative data analyses and interpretation.

To answer the first research question, university researchers referenced field notes and engaged in a reflexive process (Garcia-Iriarte *et al.* 2008). To answer the second research question, university researchers identified patterns in the members' interpretations of the data. First, the interpretations generated by separate discussion groups were grouped together by checklist item. Second, codes describing the content of members' interpretations were assigned to text. Codes were derived in two ways: by looking for similar content generated across groups in response to the same item (internal homogeneity), and looking for similarities and differences in content across items (external homogeneity) (Patton 2002). During this process, interpretations and implications identified by the university researchers were bracketed from those interpretations generated by People First members. The substantive significance (Patton 2002) of the codes arising from the members' interpretations was established by: (i) triangulation of content between groups and items and (ii) examination of the extent to which codes were in concert with or provided alternatives to a previously generated model of group capacity for advocacy (Garcia-Iriarte *et al.* 2008).

Results

Process of data analysis and interpretation

All People First members were able to participate in the first stage of the analytical process, analysing the bar graphs as a group to determine the extent to which People First members had control over meeting tasks. All group members were able to identify the rating category associated with the tallest bar graph and determine 'who did what' most frequently with the support of other group members, supporters and the visual cues provided in the bar graph. The accessibility of the method was illustrated by one member's proud exclamation of 'I got it!' after presenting and analysing one of the items in front of the group. The group reached consensus on the analysis of all items.

The second stage of the process, interpreting the data, was not fully inclusive. The discussion generated in this stage of the process varied across individual members and small groups. Of the members who participated, some did not respond to the questions, some responded only to questions about their feelings, and other members put forth detailed responses that described the reasons for change in control and implications for the

Table 2 Analysis of "Who Did What" checklist items related to the use of participation and organizational strategies

Strategy	Frequency of use
Participation Strategies	
Keeping time	3
"Microphone"	2
Big paper*	2
Round Robin	2
Planning an Action Worksheet	2
Sticker Voting	1
Supports Worksheet	0
Organizational Strategies	
Place to store things	14**
Money List	7
Copies of meeting minutes	7
Bulletin board	5
Meeting flyer	4
Papers in folders	1

*This item refers to use of a flip chart to record ideas.

**Strategy identified by group as most frequently used.

future. Depth of interpretation appeared to be related to individual communication style; those members who did not communicate verbally in either English or Spanish had difficulty contributing to the interpretation process. In addition, differences in the depth of interpretation appeared related to individual member experience. Members who had experience serving as an officer or being in charge of specific meeting tasks were able to draw from personal experience and identify potential solutions to challenges the group encountered. One example is the following exchange describing the group's use of the speaking/listening technique 'microphone':

University Researcher: "Do you guys keep time at the meeting a lot?"

All: "No."

University Researcher: "Why didn't it work out?"

Member 2 (former secretary): "Cause nobody paid attention and everyone was talking at the same time."

University Researcher: "What do you think you guys should do?"

Member 3 (former treasurer): "We should put it back on and try again"

Member 2: "And we need the microphone."

University Researcher: "Do you guys like that?"

Member 4 (President): "I think the microphone is gonna help because then people can start listening to what they say."

Reflections such as the one above from the officers that suggested they knew how and why change occurred and how it impacted the group, compared to other members' more general statements that related feelings of happiness and pride to group membership.

Perspectives of people first members regarding group capacity for advocacy

People First members' analysis indicated they were most frequently in control of eight meeting tasks, and three meeting tasks were most frequently completed in collaboration with advisors (Table 1). One meeting task, arranging transportation, was typically not completed. The group infrequently used organizational and group participation strategies, with the exception of the use of a centrally located filing cabinet in which group information and records were stored (Table 2).

University researchers extracted three primary themes from the transcripts and field notes documenting People

First members' interpretations. These themes were in regards to the type of supports that enabled a change in capacity for advocacy, a sense of accomplishment that stemmed from the group's increased capacity for advocacy and the nature of the relationship with group advisors.

During the interpretation of the data, members indicated that they used a variety of types of support to increase their capacity for running a meeting. One type of support was assistance received from other group members, as illustrated in the following quote:

University Researcher: "Does it make you feel good that [members] make copies?"

Member: "We can do something..."

Vice President: "And if somebody doesn't know how to do it, they can show that person how to do it. A member showing a member."

Other interpretations suggest that using organizational supports was a strategy that enhanced the group's ability to run the meetings. For example, in regards to the Agenda Template, one member commented: "[The agenda] tells you time to come, tells you who the president is", while the Vice President noted that while looking at the agenda "we know that [we] just keep following along with what we got to do."

Receiving support from advisors was another important type of support cited by members during interpretation. Control fluctuated on a monthly basis between shared control (People First members and advisors) and group control. That is, even those meeting tasks that People First members controlled most frequently were occasionally completed in collaboration with advisors, and those meeting tasks most frequently completed in collaboration with advisors were occasionally completed by People First members on their own. Two representative examples of this fluctuating and dynamic nature of control are the items 'Who thinks of items to put on the agenda' and 'Who makes copies of the agenda' (Figures 2 and 3). Only the items 'Who remembers to look at the agenda', 'Who takes attendance at the meeting', and 'Who brings the meeting to order' were consistently completed by People First members during the final seven months of the project.

People First members expressed a sense of accomplishment when they most frequently performed meeting tasks on their own. For example, in relation to the item 'Who makes copies of the agenda,' one member said that 'it shows us that we know how to work a copy machine.' Other members responded by sharing they felt 'good'

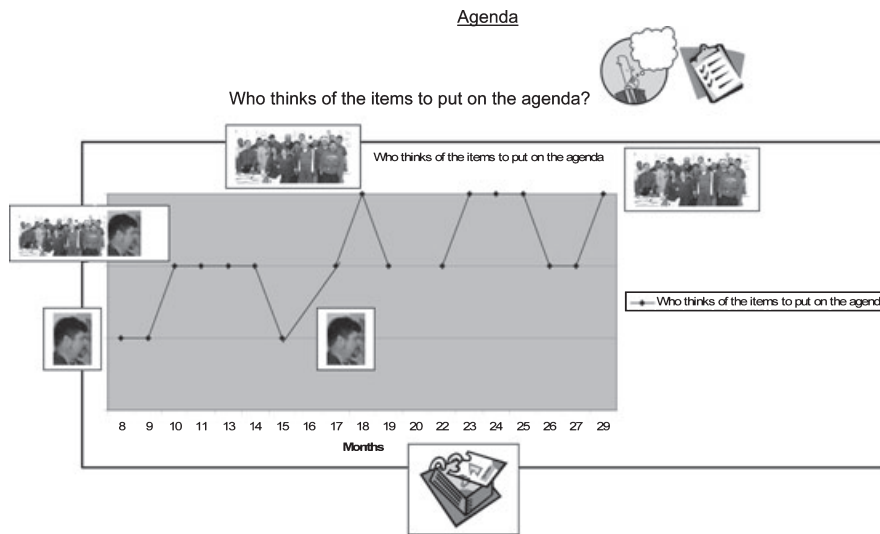


Figure 2 Results over time for item 'Who thinks of the items to put on the agenda?'

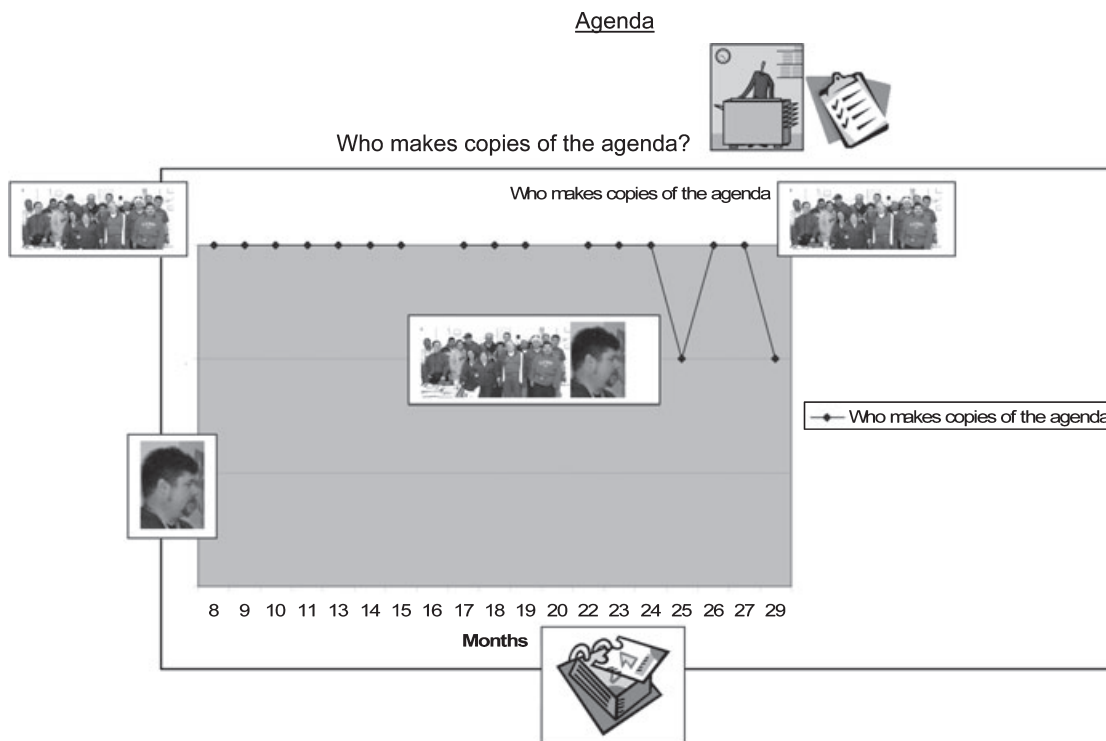


Figure 3 Results over time for item 'Who makes copies of the agenda?'

and 'happy.' Members also expressed a feeling of group pride as one member noted that because of the changes in group capacity for running the meetings "we're more united... [more] involved." When members were asked about the change from advisor control to member control, one member provided the following explanation:

"The switch of the officers... We actually just started controlling the meeting ourselves..." In fact, the experience that the officers gained from managing different tasks provided them with a deeper understanding of the support needed to run the meetings and enabled them to support the participation of other members.

Members had a positive attitude regarding the support they received from the group advisor. Member's acknowledged that the role of the advisor was to provide support to run the meeting. For example, one member explained: "Cause we didn't know all the different conferences we're going on, all the different outings, what we wanted to go on. So that's where a supporter comes in." At times, this support was essential to conducting the meeting, as one member commented that without the advisor's assistance to arrange transportation "we'd be walking!" However, advisor support was not interpreted by members as unidirectional and authoritarian, but as collaborative. For example, one member said, "We thought up ideas plus they thought up ideas also... we get out ideas and we can combine them together." Although members acknowledged the need for advisor support, they also stressed that they continued to take more control by learning how to manage meeting tasks. As one example, the Vice President noted: "Actually, we're starting to get our own email... we're trying to get ... [the state advocacy agency], if [they] get another conference going on, they'll send the email to us... the officers... or the officers and [the advisor]."

Discussion

In this study, participating in an inclusive process of data analysis and reflection enabled People First members to recall their original goal of increasing group capacity for advocacy, reflect on the progress towards their stated goal, and identify areas where the group sought to further build capacity. The findings reported in this paper highlight two outcomes that the group experienced via their engagement in the 22 months PAR process: empowerment and awareness. Regarding empowerment, the group's increased capacity for running a meeting led to a sense of pride and accomplishment. Other research with self-advocacy groups has highlighted the importance of group pride and accomplishment as a legitimate and valued outcome of advocacy (Goodley 2000). The second outcome is awareness. The opportunity to reflect on the control held by members over the 22 months enhanced the group's awareness of their capacity for advocacy. While members reflected monthly on their capacity for advocacy by completing the checklist after each meeting, the data derived from each meeting were subject to contextual influences on group control. This included fluctuations in use of strategies, member attendance and agenda topics discussed. Therefore, data from a singular meeting

provided an incomplete understanding of the nature of the group's capacity for advocacy. However, reflecting on data gathered over time revealed that members had control of the group's direction, regardless of the number of individual tasks the members controlled at any one meeting.

Over the 22 months of data collection, all meeting tasks but one were most often controlled by members, or jointly controlled in collaboration with the group advisor. Members most frequently controlled meeting tasks that were consistent, formal, concrete, and often time specific tasks associated with running a meeting, such as making copies of the agenda and taking attendance. Members shared control with advisors for novel meeting tasks that required contextual or situational decisions or involved the use of advanced leadership and group facilitation skills, such as thinking of agenda topics and following the agenda during the meeting. These tasks required members to communicate across multiple organizational levels (officers, members, advisors and outsiders); seek and gather information aligned with the group mission and purpose; use organizational processes to document ongoing group activities and achievement of group goals; and implement group process techniques during meetings to enable the participation of all members. It is possible that member control over these tasks will increase as members gain experience through continued exposure to leadership roles in a 'learning through action' process. The responses generated from former and current officers suggest that experience leads to increased insights regarding group changes in capacity and enhanced ability to identify solutions to group challenges.

On a month to month basis, control over meeting tasks fluctuated between members and advisors. While shifts in control from people with intellectual disabilities to others are considered threats to self-advocacy and a PAR approach, it is important to note that People First Members did not express dissatisfaction about their relationship with the advisors. Rather, People First members appreciated the role the advisor played in getting the members access to information, arranging logistics of transportation and event organization and providing them with ideas for activities. Other studies have noted that when advisors provide support that is responsive to the needs of the group and focused on the strengths of the group, members perceive the support as positive and part of a collaborative and respectful relationship (Goodley 2000; Townson *et al.* 2004; Schoeters *et al.* 2005). The analysis and reflection from People First

members provides further evidence that this type of advisor support enabled the group to be in control and feel empowered.

The members' responses to the 'Who Did What' checklist data indicated that a variety of types of support enabled the group to increase their capacity for advocacy, including member support, advisor support, and strategy supports (Garcia-Iriarte *et al.* 2008). The importance of these supports and the dynamic interaction between the different types of supports may explain why control often fluctuated between member control and shared member/advisor control. Any change in how these supports were delivered or the absence of any one of these supports in any given month could mean that members were not able to have control over a meeting task. This dynamic interaction between support and member control provides additional support to our previously hypothesized continuum of self-advocacy participation, advisor control, and group control (Garcia-Iriarte *et al.* 2008). These findings also imply that researchers should use caution when measuring control and self-advocacy at only one point in time. Rather, a more complete picture of self-advocacy and control may emerge when examined over time. Future research may consider documenting actual use of specific supports on a monthly basis along with documentation of member control in order to systematically explore the relationship between support and group capacity for running a self-advocacy meeting.

The outcomes of the data analysis and interpretation process suggest that all members were able to participate in data analysis. Several key components of the analysis phase may have supported an inclusive process. The first component was the use of bar graphs. Instead of looking at 'raw numbers,' the bar graphs presented the data one item at a time. In this study, since the interest was in examining change in a specific item and not of comparing one item to another, presenting the data in such a way did not jeopardize the rigour of the analysis. In essence, the use of bar graphs broke data into manageable chunks of information. This approach of 'reducing' data into chunks that are needed to answer a question and excluding data irrelevant to a research question may be one approach to an inclusive data analysis process. However, if university researchers determine which data are relevant and irrelevant to the research question, it is possible that some data that would be important to collaborators with intellectual disabilities would not be considered for analysis. Collaborating with people with intellectual disabilities to identify the questions guiding the analysis may help

ensure the process of analysis is transparent yet inclusive.

A second component was the use of a modified focus group approach in which People First members worked as a group to analyse data. This approach had two benefits. First, it enabled individual members to marshal an existing supportive social network and created a safe environment. Second, it created an environment that fostered a 'debate,' something that is common among researchers analysing data. Reaching consensus as a group also served as a form of peer-review. In several instances, individual members provided responses with which the majority of the members did not agree. The members had an opportunity to speak out and to offer their opinion on what the data signified. Doing this minimized the risk of any individual being labelled as 'wrong' and enabled the group to work together to identify the analysis best supported by the data. Conducting analysis with groups of people with intellectual disabilities rather than individuals creates an inclusive process through social support and helps to counterbalance the power differentials typically held between researchers and people with intellectual disabilities (Walmsley 2004).

A third component was the People First members' familiarity with the checklist questions, response categories, and pictures associated with each item. The process of completing and, at times, administering the 'Who Did What' checklist meant that most members were already familiar with the meaning of individual items and rating scale categories. As a result, members were able to ground the analysis and interpretation of the data in their lived experiences. This strategy of building upon concepts familiar to collaborators with intellectual disabilities is another strategy that facilitates an inclusive analytical process.

However, not all members were able to access and participate in the interpretation of the data. The strategy used to interpret the data, small group guided discussion, relied on verbal communication and therefore was not accessible to members who did not communicate in this manner. This finding points to the importance of using a variety of strategies in collaborative research, especially strategies that enable persons to share their perspectives non-verbally. Other researchers have acknowledged that involvement in data analysis requires a degree of verbal ability (Tuffrey-Wijne & Butler 2009). Other collaborative research projects may wish to consider using support strategies that enable persons who do not communicate verbally to share thoughts and feelings non-verbally.

Limitations

One limitation to this study concerns the generalizability of the process and findings; the findings may be reflective only of this particular self-advocacy group and their experiences. In addition, the findings may not generalize to other self-advocates with fewer or more functional skills. However, the goal of PAR is not to generalize to all settings, but to enable change that is meaningful for and relevant to a local community (Freire 1970).

While the analysis and interpretation process used strategies to maintain a reliable analysis and inclusive collaboration, the credibility of the findings reported here may be called into question by members' exclusion in the content analysis of their discussion and in the creation of this manuscript. Though beyond the original scope of the study, the university researchers are aware that this study stopped short of incorporating an inclusive authorship strategy. Other scholars have noted the tensions and challenges that arise regarding publication in collaborative research; factors such as complex and highly technical analytical approaches, conflicting schedules, and different values regarding the importance of publication pose many barriers to collaborative analysis and publication of research results (Israel *et al.* 2005; McClimens 2008). This project encountered similar barriers in the process of interpretation and dissemination.

To address this limitation, the university researchers used several strategies to ensure the members' analysis and interpretation was clearly conveyed in this manuscript. One, the university researchers provided thick description of the process used to collaborate with the group to help the reader understand the nature of the data produced through the collaborative process. Two, when writing the results section, the university researchers attempted to limit any additional interpretations made from the data by reflexively asking 'Does this sentence convey the perspectives of the members or reflect our interpretations of the experience as university researchers?' Three, interpretations and implications identified by the university researchers were bracketed from the results and instead presented in the discussion section.

Conclusion

This paper described the process used by a group of self-advocates and university researchers to analyse and interpret data collected during a PAR project to increase the group's capacity for advocacy. In summary, all members

were able to participate in the data analysis, but not all members were able to access and participate in the interpretation of the data. Findings suggest that strategies such as visual representation of data, group analysis, and familiarity with data collection tools foster inclusive analysis and interpretation. Members' interpretations of the data suggest that the group felt an increased sense of empowerment and heightened awareness as a result of their involvement in ongoing reflection. This study highlights how inclusive process of data analysis and interpretation can provide a final opportunity for reflection during engagement in the PAR process.

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